

The International Cluttering Association

ASHA 2008

Providing Worldwide Cluttering Education: Accomplishments of the International Cluttering Association (ICA)

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International Focus

Mission focus:

Given that a significant portion of cluttering research has been conducted outside the United States, it is of primary importance to the ICA that representation be international.

Roadblocks:

- 1) Lack of ability to frequently meet face to face
- 2) Recruiting representatives in under- represented countries.

Steps taken:

- 1) A committee of international representatives was formed.
- 2) A chair of this committee was selected who is well known in the field of speech-language pathology internationally, as well as an advisor who has worked extensively in the field of international research. Care was taken to create a balanced international representation in the ICA.
- 3) The ICA maintains an active and two-way communication with participating countries.
- 4) Via its website (currently translated into 5 languages) and email communication, the ICA provides unique resources for countries where little is known about cluttering. In contrast, other countries may have unique resources, ideas, and suggestions that can be shared with the ICA, particularly related to support systems. Such new support models can be solutions for other countries not yet associated with the ICA. The ICA provides opportunities for such unique collaboration to be heard and implemented.

Future Plans:

- 1) Continued translation of website information into other languages.
- 2) Development of surveys to the international membership to continue the exchange ideas for increasing awareness worldwide.
- 3) Continued recruitment of ICA representatives worldwide.

Consumer Issues

Mission focus: Given that those with cluttering offer a personal perspective to cluttering, it is of primary importance to the ICA that consumers, i.e. people with cluttering, be represented and heard.

Roadblocks:

- 1) The people with cluttering have the most information about the personal experience of cluttering. However, due to a lack of awareness in this population, many who might participate as consumers have yet to be identified with cluttering.
- 2) Among the public, cluttering is often associated with disorderliness of things rather than a communication disorder. These factors create a circular problem with raising public and professional awareness in that they present roadblocks to gaining media publicity and furthering the mission of the ICA. **There is currently a significant lack of awareness among the media regarding the importance of their role in raising awareness of cluttering. This continues to perpetuate the lack of understanding among the general public that cluttering is a very real communication disorder with significant life consequences.**

Steps taken:

- 1) A consumer committee was created and is headed by consumer co-chairs, Joseph Dewey and Peter Kissagizlis, who have been proactive in sharing their insights about their experiences with cluttering and increasing awareness of the disorder.
- 2) Consumer issues have been a primary area of focus with links on the ICA website to support groups (both online: <http://groups.yahoo.com/group/cluttering/links>; and within specific countries: www.speakingout.org.uk).
- 4) A means for guiding the consumer in locating clinicians with experience diagnosing and treating cluttering is currently being established.
- 5) The ICA maintains close contact with consumer representatives and support groups, frequently seeking the input of people with cluttering and their family members.
- 6) A recent survey among support group members regarding use of person-first terminology was initiated in order to ensure consistent use of preferred terminology among the ICA as an organization. Although opinions were varied among the group as to whether or not to use person-first terminology, the general consensus was that "cluttering" is preferred over "clutterer," and acronyms are considered more impersonal than "clutterer," and can be confusing "jargon" to the general public. Therefore, the ICA tends to use the terms "people with cluttering," and to avoid acronyms where possible.

Future Plans:

- 1) Continued brainstorming among ICA members and consumers to take steps toward raising awareness of cluttering at the grass roots level and beyond.
- 2) Advocating for the presence of cluttering presentations and workshops at national and international professional and self-help fluency conferences to further the education of speech-language pathologists (SLPs) in cluttering.
- 3) As SLPs learn to identify cluttering in their clients, they will be encouraged to acquaint these people and their families with the ICA and refer them to support groups, so that the pool of spokespeople for cluttering will broaden.
- 4) The ICA continues to seek high profile names of those with cluttering to increase media response.

Education

Mission focus: Given that there is a lack of education among both the public and professionals regarding the communication disorder of cluttering, education of these parties is of primary importance to the ICA.

Roadblocks:

- 1) Lack of awareness among SLPs, who should be the primary source of information for the consumer.
- 2) Lack of guidelines for university teaching.

Steps taken:

- 1) Resources have been and continue to be posted on the website related to the areas of general information about cluttering, as well as information regarding assessment and treatment.
- 2) **SOURCES OF INFORMATION FOUND ON THE "ICA" WEBSITE:**
 - CLUTTERING: A Clinical Perspective (Myers & St. Louis, 1996)
 - Guidelines for a Cluttering Assessment
 - Daly's Predictive Cluttering Inventory
 - Software Downloads such as Bakker's Computer-based Cluttering Assessment Tool (CLASP)
 - Clinical materials
 - Bibliography on cluttering (national and international resources)
 - T.R.A.D.E. (Treatment, Research, Awareness, Diagnosis, Education), a quarterly newsletter
 - Media material demonstrating cluttered speech

- Links to materials such as the DVD (St. Louis & Myers) on cluttering (available through Stuttering Foundation of America ASHA exhibit table or www.stutteringhelp.org)

Future Plans:

EDUCATIONAL OPPORTUNITIES:

- Division 4-sponsored Web forum on cluttering- **Monday, January 12, 2009 8-10M EST**
(<http://www.asha.org/Forums/messages.aspx?ForumID=8732>)
- Sponsoring the **Second World Congress on Cluttering** (tentative 2010)
- Organizing SLP cluttering training workshops in the US
- Guidelines for university teaching

Collaborative Research and Partnerships: Academicians/Researchers, Clinicians, Consumers

Mission focus: The ICA intends to foster the development of partnerships among consumers, academics/researchers, and clinicians that lead to collaborative, evidence-based research projects. The purpose of these projects is to ultimately improve communication function and quality of life for people with cluttering.

Roadblocks:

- 1) Lack of time allotted for teaching cluttering in academic programs.
- 2) Lack of evidence-based materials for university teaching.

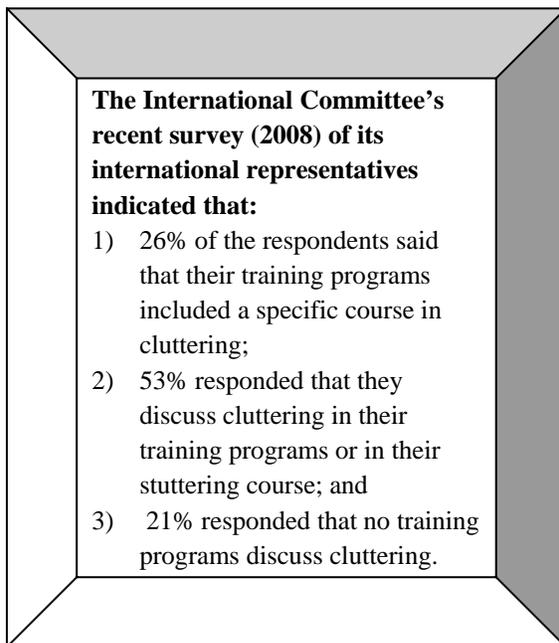
Steps taken:

- 1) The ICA Research/Academic committee continues to identify areas for future study
- 2) The Research/Academic committee has identified areas of future study, including:
 - Establishing acoustical, psychological, central nervous system and behavioral characteristics of cluttering leading to a universally agreed upon definition of cluttering
 - epidemiology for the determination of age of onset; risk factors
 - Differential diagnosis of cluttering and coexisting disorders
 - Improvement of cluttering evaluation

- Development of systematic treatment protocols
- Studies on professional and public awareness of cluttering.
- 3) Survey of international representatives was completed regarding current coursework on cluttering in SLP training courses worldwide (Reichel, 2008)

Future Plans:

- 1) Online article and discussion forum regarding current needs in defining cluttering, with end goal the development of collaborative research projects for better defining cluttering
- 2) Special Issue of *Perspectives* devoted to cluttering due out in August 2009
- 3) Edited textbook on cluttering (anticipated 2009) featuring evidence-based chapters from international experts in one volume



The following USA definition is the most recently revised version of the working definition of cluttering (St.Louis, Raphael, Myers and Bakker, 2007):

Cluttering is a fluency disorder characterized by a rate that is perceived to be abnormally rapid, irregular or both for the speaker (although measured syllable rates may not exceed normal limits). These rate abnormalities further are manifest in one or more of the following symptoms: a) an excessive number of disfluencies, the majority of which are not typical of people who stutter, b) the frequent placement of pauses and use of prosodic patterns that do not conform to syntactic and semantic constraints; and c) inappropriate (usually excessive) degrees of coarticulation among sounds, especially in multisyllabic words.

For more information on the International Cluttering Association, please contact:

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Or request a membership form from:
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<http://associations.missouristate.edu/ICA/>